Letter to the Editor

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To The Editor,

We would like to commend the qualitative research article "Epilepsy in children and adolescents: Disease concepts, practical knowledge and coping" by Pauschek et al [1], which provides much needed information on the under-examined area of children's own perspectives of their epilepsy [2]. They used 'child-friendly' approaches of a structured interview and drawings tools to facilitate children's involvement and participation [3].

However, the structured interview appears to be, as described, a question-answer session with associated correct and incorrect responses, some of which were validated by paediatric neurologists. This raises the questions as to whether the authors were trying to truly capture children's own understanding of epilepsy and what it means, either correct or incorrect, or alternatively whether they were attempting to gauge whether children have a 'medically correct' grasp of epilepsy. Although both of these options are indeed useful and hold merit, they should not be confused.

A child's understanding and associated description of how they experience a seizure is of use and enables paediatric neurologists to better appreciate a child's own lived experience of epilepsy. Alternatively, as suggested by the authors, knowing whether children can 'correctly' describe their seizures holds insights into their diagnosis and diagnostic process for paediatric neurologists. Consider whether you would necessarily seek to ensure an adult's responses were correct when asking them how they experience a seizure?

Additionally, notwithstanding manuscript word limit, a fuller discussion surrounding children's actual described understandings of epilepsy would offer further insight into how they comprehend their condition and whether this comprehension is underpinned by biomedical or social knowledge. This level of nuance of children's perspective can assist paediatric neurologists in their delivery of relevant and appropriate epilepsy information and support to children and their parents.

Furthermore, again respecting the word limit, more details on the how the study was carried out would have been useful. In particular, information around debriefing the children regarding their interview questions and who carried out the interviews (their own consultant or a stranger) would have been welcome. For instance, how were children supported after being asked if their disease was contagious and whether they thought they were worse off than other children without epilepsy? Such concerns could have influenced how a child responds to questions.

In spite of these caveats, the research presented by Dr Paucsckek and colleagues [1] extends the much-needed evidence-base examining children's own views and experiences of being diagnosed and living with epilepsy. It also reminds us that there is still much work to be done in this area.

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Ethical publication statement
We confirm that we have reviewed the Journal's position on issues involved in ethical publication, and the work described in this paper is consistent with those guidelines.

Conflicts of interest statement
There are no known conflicts of interest associated with this publication.

References
[1] Pauschek J, Bernhard MK, Syrbe S, Nickel P, Neininger MP, Merkenschlager A, Kiess W, Bertsche T, Bertsche A. Epilepsy in children and adolescents: Disease concepts, practical knowledge, and coping. Epilepsy Behav 2016; 59:77-82.
[2] Harden J, Black R, Chin RFM. Families' experiences of living with pediatric epilepsy: A qualitative systematic review. Epilepsy Behav 2016; 60:225-237.
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